



An Australian Government Initiative



Curtin University



*26th International Conference of Alzheimer's
Disease International Toronto Canada
26 – 29 March 2011*

**Exploring inter-sector
Communities of Practice (COP)
as a strategy to support best-
practice palliative care for
people with dementia**



Local Palliative Care Grants Program: Round 5

<http://upload.wikimedia.org/wikipedia/commons/8/8c/As-map.png>

Background

Research Project funded by Australian Govt Department of Health and Aging through Local Palliative Care Grants Program

4 organisations partnered to coordinate this research in two locations:

- Perth, WA (metropolitan) - Alzheimer's Australia WA and Curtin Health Innovation Research Institute, Curtin University and
- Launceston, Tasmania (regional/rural) – Wicking Dementia Research and Education Centre and the Menzies Research Institute, University of Tasmania and Alzheimer's Australia Tasmania

18 month Project commenced in Mar 2010 final report due July 2011

Project Aim – develop and test Communities of Practice as a means to enhance care and care continuity for people with dementia for whom death within 6 months is not surprising (target population)



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Introduction

In Australia, people with dementia receive care from a range of care professionals in various settings – in their own home, in rooms of the general practitioner or medical specialist, in residential aged care facilities (nursing homes) and in hospital.

For individuals with severe or end stage dementia and their families, the potential for variation in and fragmentation of end-of-life care provision is increased as their dementia care and support needs increase, frequently involving multiple care professionals. This care may be supplemented or supported by specialist palliative care services.

An Australian Government Initiative

Alzheimer's Australia WA Ltd
Living with dementia

Curtin University

Alzheimer's Australia Tas
Living with dementia

Monash Research Institute
An Institute of the University of Tasmania

Common Understanding

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Frame of Reference

People working in the area of dementia are extraordinarily committed and passionate about what they do and they all have knowledge of dementia according to their area of practice. However, their approach and the information and support they provide to people with dementia and their families in the context of end-of-life care will differ.

The reality is that people work as individual care practitioners or members of a team within a general or specialist medical practice, hospital, residential aged care facility or community service provider. They don't normally work with an awareness or understanding of what other practitioners do, nor do they necessarily seek to find out.

"The sensual eye is just like the palm of the hand. The palm has not the means of covering the whole of the beast "

"The Elephant in the Dark"

Story of an elephant brought for exhibit in a dark room. A number of men feel the elephant in the dark and, depending upon where they touch it, they believe the elephant to be like a water spout (trunk), a fan (ear), a pillar (leg) and a throne (back).

Interpretation by Rumi, a 13th century Persian poet and teacher of Sufism.

Rumi uses this story as an example of the limits of individual perception.

Communities of Practice

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<http://www.freedigitalphotos.net>">Image: FreeDigitalPhotos.net</p>

Project Aims and Objectives

What if we could deal with and overcome the contextual barriers that exist in our everyday practice to develop a generalist holistic approach to enhance the quality of life, and quality of death of a person with dementia with a life limiting disease? And in so doing, we better equip people with dementia and their families to deal with end-of-life issues and needs.

This Project aims to do this by:

- engaging with people who are passionate about making a difference, who work in settings providing care to people with severe or end stage dementia, to become members of and form a Community of Practice (COP).
- facilitating opportunities for COP members to enhance their knowledge and expertise through ongoing interaction (learning as a social experience) and development of practice resources (both educational and informational) identified by COP members as needed to support best practice.

The establishment of COPs in 2 distinctly different Australian locations - WA and Tasmania, illustrates how the Communities of Practice model can be developed according to the specific needs and requirements of members in each location.

"If each had a candle and they went in together the differences would disappear."

The Elephant in the Dark"

Rumi, 13th Century Persian poet and teacher of Sufism



http://www.freedigitalphotos.net/images/view_photog.php?photogid=1499>Image: Ambro / FreeDigitalPhotos.net</p></div>

Project Teams

Who better to undertake and guide the project than a consortium of researchers and practitioners working in dementia? This consortium was able to provide a Project Coordinator who is an extraordinarily good communicator, an organiser with an eye detail, who also keeps a close watch on the Project deliverables and timelines (for both funder and COP) and a Resource Development Officer.

Team Tasks

- Set up Project Reference Group (*comprise geriatrician, psychiatrist, GPs with aged & palliative care interest, nurse practitioner in aged care, pharmacist, counsellor in dementia, managers in aged and palliative care services, consumer whose family member has dementia*)
- Set up electronic communication tool - CareSearch Webpage and Forums
- Establish a local COP, with representatives across the sector:
 - In WA - Annesley Residential Aged Care Facility (Uniting Church Homes); Rowethorpe Medical Practice; Southern Cross Community Aged Care Services; Bentley Hospital – Wards 4 & 10, Alzheimer’s Australia WA – Respite and Counselling & Support Services
 - In Tasmania – COP members comprise predominantly medical practitioners, palliative care specialists, hospital registrars

Steps to change practice

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Methodology

Uses an action research approach, which provides a structure for the process of practice change. COP members were introduced to the approach and how it worked, in order for modelling of the change process to occur

An important component was encouraging COP members to think differently, to be prepared to question current practice and protocols within their workplaces, and come up with solutions to problems. Through support and mentoring it is hoped COP members will continue to implement this approach in their workplaces

- In WA – to engage right brain thinking using various techniques including speed thinking and a “placemat” session
- Whereas in Tasmania – they closely followed the action research methodology and cycles of engagement

Baseline evaluations were conducted involving key informant and family carer interviews and staff palliative care surveys to scope the issues.

- In WA the COP members considered the issues and what they felt needed to be addressed, they identified 3 common concerns:
 1. staff communication
 2. support for the family
 3. reassurance for the person with dementia



http://www.freedigitalphotos.net/images/view_photog.php?photogid=901">Image: Michelle Meiklejohn / FreeDigitalPhotos.net</p>

Implementation

For the three areas of concern, COP members identified changes & resources they required to better support people with dementia and their families and enable practice changes within their organisations:

1. Staff Communication (ie. communication and information, palliation, improve understanding of disease process, how to dialogue with family)

- which staff needed to be influenced
- what they needed to know
- how they were going to influence them

Developed - Educational materials

2. Family Support

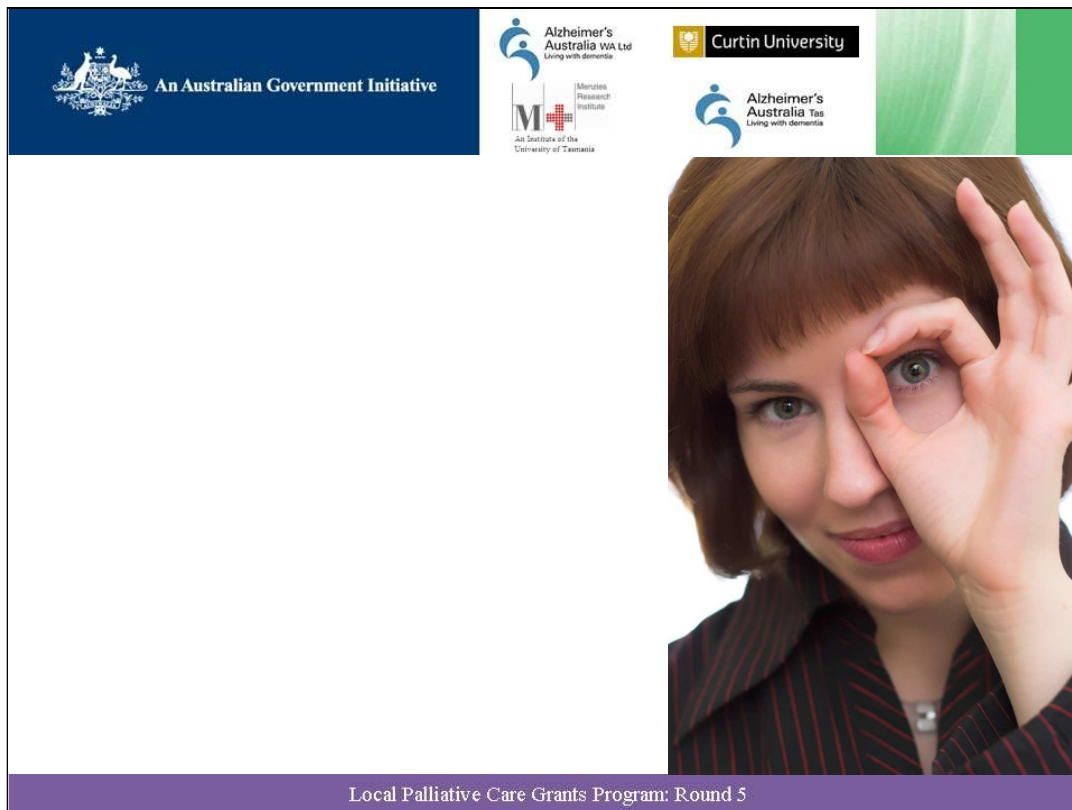
- how to mentor and support family to navigate complex system of end-of-life care when case management model not possible

Developed – Key Contacts list, Information sheet, Dementia Information booklet, Key Elements of a Palliative Approach booklet

3. Support for the person with dementia

- how staff can help overcome perception of fear, identify the cause, improve environment, learn about medical and non medical interventions

Developed – Personal Life History Booklet, Client Personal Preference Information, Key Elements of a Palliative Approach booklet



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Discussion

Critical elements in implementing the Community of Practice COP in WA:

- Ongoing commitment of COP members and their organisation's support for them
- COP members (Change Champions) encouraged to set up support network within their own organisation (a mini COP) to address scenarios when other staff not as enthusiastic, not see practice change as necessary or as priority
- Project Team ensure all COP members have a voice within meetings and COP members treated with respect (*If say organise meeting for an hour commencing at 5pm, ensure it starts on time and not run over time, provide pleasant meeting environment, include refreshments etc*)
- Efficient organisation by Project Team - provide resources if running out, keep on track with handing out evaluations etc
- Project Coordinator - frequent contact, visits and assistance to COP members with process as required
- Project Team mindful of not offering or providing solutions to problems, instead work with COP members to find solutions themselves

COP members are now exploring ways of sustaining commitment and engagement in practice change beyond the life of this Project

The slide is titled "Social capital" in a bold, black font. At the top, there are four logos: "An Australian Government Initiative" with the coat of arms, "Alzheimer's Australia WA Ltd Living with dementia", "Curtin University", and "Alzheimer's Australia Tas Living with dementia". Below the logos, the text "Social capital" is centered. In the bottom right corner, there is a photograph of a hand holding a white piggy bank. At the bottom of the slide, a purple bar contains the text "Local Palliative Care Grants Program: Round 5".

http://www.freedigitalphotos.net/images/view_photog.php?photogid=1499">Image: Ambro / FreeDigitalPhotos.net</p>

Preliminary Findings

It is too early to say whether the end-of-life care of people with dementia and their families has been enhanced through the outcomes of this Project - the practice changes and development of resources . However we can state:

- It is possible to overcome organisational, contextual and personal (practice insecurities and isolation) barriers to bring together a group of care professionals to identify different ways of doing things that can achieve the outcomes they want for people with dementia and their families
- Connections with and between COP members and their organisations increased
- There is commitment for ongoing practice change within COP organisations
- A consistent message based on a common understanding of a palliative approach in dementia care developed within and between COP organisations
- Quality information resources for people with dementia and family carers that COP members recognise as relevant for use across all settings – acute and primary care, community and residential aged care
- A suite of quality educational materials developed to support practice change and integrated into ongoing staff training within COP organisations
- Staff report value in participating in education sessions developed to support practice change
- In WA educational material will be delivered through sector wide training by the Dementia Training Study Centre, in conjunction with COP members



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Conclusion

As practitioners we struggle to acknowledge and provide good end-of-life care and support to people with dementia and their families.

A primary benefit to the person with dementia from this Project is the strengthening of the link between the palliative care approach and end-of-life care for people with dementia.

We now have an enhanced palliative care resource (WA Dept of Health – Palliative Care Resource Kit) that now includes material on the care of people with dementia, a suite of educational material on palliative care for people with dementia, and a set of practice tools, if used consistently, that could better connect and inform the providers of end-of-life care for a person with dementia

Project Resources

Contact:
Jan Akers j.akers@curtin.edu.au <http://www.caresearch.com.au>

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In Summary

- Sample of Project Resources
- Contact details for WA Project Coordinator
- Website
- The final project report will be ready for the Australian Government in July 2011, and the Consortium fully intends to publish the outcomes of the project.
- The Investigative team is preparing an application for competitive funding later this year to extend the project to study one or two aspects of palliative dementia care in more detail.

Project Team members:

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